

Report

Project Leadership

Effecting Change, One Parent at a Time



Prepared By

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FAMILY VOICES
of California

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ABOUT FAMILY VOICES OF CALIFORNIA: Family Voices of California (FVCA) is a state-wide collaborative of locally based parent-run centers working to ensure quality health care for children and youth with special health care needs.

ON THE COVER:

Project Leadership graduates Kausha King and Daniel Vasquez providing the parent perspective on the California Children's Services panel at the 2015 Family Voices of CA Health Summit.



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Abstract

Families of children and youth with special health care needs (CYSHCN) have had significant real-world experiences that could help make health care policies and administration more family-centered and culturally competent. However, many lack the training and experience to make their voices heard. Family Voices of California's (FVCA) *Project Leadership* was designed to increase the capacity of families to partner in the development and oversight of services, systems and programs upon which they and their children depend. *Project Leadership* features a comprehensive training curriculum, paired with mentoring and support, that prepares families to build partnerships with professionals and engage in public policy advocacy on behalf of CYSHCN. An independent evaluation found that program graduates from diverse backgrounds showed significant improvement in leadership skills and confidence in their ability to advocate. In the project's first two years, 79 family members of CYSHCN completed the training and began active participation on a variety of committees and planning bodies; they gave testimony at state and local hearings and had their stories featured in the media.

Background

Challenges in California for Families of Children and Youth with Special Health Care Needs (CYSHCN)

The Maternal and Child Health Bureau (MCHB) defines children with special health care needs as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

An estimated 1 in 10—approximately 1 million—California children under age 18 has a special health care need using this definition.¹

MCHB has identified six core outcomes to promote the community-based system of services mandated for all children and youth with special health care needs (CYSHCN). As the Lucile Packard Foundation for Children's Health has reported, California fares poorly in comparison with other states on many of the indicators of these outcomes:²

- Nearly half of California children with special health care needs do not receive effective care coordination, which is a central component of quality health care. The state ranks 46th in the nation on this measure.
- More than 40% of California's children with complex health needs have a difficult time obtaining community-based services, such as finding doctors and scheduling appointments.
- More than 4 in 5 children with special health care needs in California do not receive care that meets federal minimum quality standards.
- California ranks last in the nation on the percentage of children with special health care needs whose families experience shared decision-making with health care providers.

These poor rankings are not surprising given the multiple health service systems in California for CYSHCN that are extremely complex and difficult to navigate, even for many professionals in the field. Meanwhile, legislators and health care policymakers do not always understand the implications to CYSHCN and their families of the health care decisions they make, such as eligibility restrictions, service cuts, or procedural hurdles. Adding to the challenge, California's term limits for state lawmakers mean that the legislative education process needs to be continual.

1 Children with Special Health Care Needs (CSHCN): A Profile of Key Issues in California, Child and Adolescent Health Measurement Initiative, Lucile Packard Foundation for Children's Health, January 2013 accessed 4.14.15 at http://cshcn.wpengine.netdna-cdn.com/wp-content/uploads/2013/01/Christy-report_01-22-13.pdf

2 Ibid.

Benefits of Family Involvement

One of the key MCHB outcomes is that “Families of children and youth with special health care needs partner in decision-making at all levels.”

The active involvement of families of CYSHCN in health care decisions and policy has the potential to address many of the state’s challenges and help make California’s services for CYSHCN more effective and responsive. In her *It Takes a Family* report, Maryann O’Sullivan has identified a number of ways in which key objectives for family involvement can be achieved.³

- **Increased family-centered perspective:** Families are the experts regarding their children’s needs and experiences with California’s services for CYSHCN. They can provide the critical perspective needed to advance coordinated, family-centered care.
- **Increased cultural competence:** By including parents who reflect the demographics of families being served, government agencies can increase the cultural competence and family-centered perspective of their decision-making bodies and of the services they provide.
- **Increased effective outreach to other parents and family members:** Parents are arguably the best and most trusted resources for other parents in their communities. Similar to the rationale for staffing parent support organizations with parents and family members, including families in decision-making on government policy entities increases the capacity of an agency to access harder-to-reach communities.
- **Increased advocacy in the community:** When family members are included on policy entities they can serve in the community as credible advocates for needed support.
- **Increased capacity of family members:** By involving parents in decision-making related to policy and governance in a structured, supportive way, agencies can increase the capacity of individual parents to participate in the short term, as well as to become increasingly engaged in additional productive long-term roles.

Barriers to Greater Family Participation

Family members may be very interested in sharing their experiences with policymakers but many lack the skills, tools and support they need to engage in advocacy on behalf of their children.⁴

Many parents have never served on a committee or board and have not had experience working with local or state legislators. They may not have an understanding of local or state government, how bills are passed, or how policy decisions are made. Training alongside their peers can help prepare parents for this kind of participation, but the schedule of some trainings makes it too difficult for working families of CYSHCN to attend.

Even after completing a leadership training program, parents can find it hard to put their training into practice. They may not know where to begin to find involvement opportunities or what they

³ *It Takes a Family: An Analysis of Family Participation in Policymaking for Public Programs Serving Children with Special Health Care Needs in California*, Maryann O’Sullivan, Lucile Packard Foundation for Children’s Health Issue Brief, May 2014.

⁴ Jim Conway, Bev Johnson, Susan Edgman-Levitan, Juliette Schlucter, Dan Ford, Pat Sodomka, & Laurel Simmons. “Partnering with Patients and Families To Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future”, June 2006, Institute for Family-Centered Care.

need to do to make their voices heard. And many without experience in advocacy lack the confidence in their ability to partner with decision-makers without ongoing support.

It is also important to note that these barriers affect the diversity of families able to attend trainings, serve on committees and pursue relationships with decision-makers. In the past, only a small number of parent leaders around the state were serving on boards and committees and providing information to legislators and policymakers. Because the group was small, they could not reflect the true diversity of language, ethnicity, income, region and health care issues that are representative of California's population. *Project Leadership* was designed and implemented to address these barriers and enhance family participation in programs and policy-making in California.

Methods

Curriculum Background

Project Leadership: Background and Approach

Family Voices of California (FVCA) is a collaborative of local parent-run centers working to ensure quality health care for children and youth with special health care needs throughout California. FVCA's *Project Leadership* was designed to increase the capacity of families of children and youth with special health care needs (CYSHCN) to partner in the development and oversight of services, systems and programs upon which they and their children depend. In addition to a comprehensive training curriculum, the project includes support services designed to reduce the barriers that often limit parent participation.

The initial approach grew out of Partners in Policymaking California (PIPCA), an affiliate of Minnesota's internationally recognized program that provides competency-based leadership training for adults with developmental disabilities and parents and care partners of young children with developmental disabilities. In partnership with The Arc of CA, CA Association of Family Empowerment Centers, People 1st of CA and the Family Resource Centers Network of CA, PIPCA offered a 130-hour certificated program for families and consumers that took place during eight weekend sessions—one each month for eight months—and had a strong focus on influencing legislative policy at the state level. Sessions required an overnight stay of participants. There was one PIPCA session per year in one of four regions (north, central, south, Los Angeles County). (PIPCA is no longer active in the state.)

FVCA wanted to develop a training that would make family participation easier: one that would be less time-intensive and not require overnight stays, which can be challenging for parents of CYSHCN. FVCA also wanted to broaden eligibility to families who wouldn't qualify for PIPCA under its developmental disability criteria. Unlike PIPCA, which is focused on state legislation, FVCA also wanted to promote advocacy at local and regional levels as well as the state level, and prepare families to work effectively with health care providers for systems change.

Curriculum Development

Funded by a grant to FVCA from the Marguerite Casey Foundation in 2004, the *Project Leadership* curriculum was developed as a collaborative statewide effort. It is based on Partners in Policymaking as well as on two other successful leadership models: the Arizona Department of Health Services, Office for Children with Special Health Care Needs; and the Florida Institute for Family Involvement. FVCA met with these groups, discussed their models, and identified strengths and challenges. As a result, FVCA formulated a model that would work best for California's CYSHCN, considering the size and diversity of the state.

Project Leadership was conceived as a comprehensive, seven-session training curriculum with integrated and continuing support services including mentorship, resource information, peer support, staff support and linkages with FVCA's statewide network. By providing families with convenient, locally focused training, free childcare during trainings, ongoing support and continuing linkages to

involvement opportunities, the project helps reduce the barriers that have kept parents of CYSHCN from participating as effective public policy advocates.

In 2007, 24 FVCA agency representatives from across the state—mostly parents of CYSHCN—met to review the curriculum and provide input on content, organization and activities; this input was incorporated into the current curriculum.

Over the next several years, FVCA piloted aspects of the curriculum to secure input and feedback from families and professionals and to assess its effectiveness:

- A number of the *Project Leadership* training chapters were presented at annual state Family Resources and Supports Institute meetings in 2008 and 2009, receiving very positive feedback from participants.
- FVCA member agencies also used the “Telling Your Story” training chapter to prepare parents to participate in an annual Health Summit and Legislative Day convened by FVCA in the state capitol.

“Project Leadership helped build my confidence to advocate for my child and other children with special health care needs. It also gave me the strength and confidence to continue pushing to get services and make sure programs continue happening for children.”

Project Goals

The vision of *Project Leadership* is that families of CYSHCN and consumers will be able to effect health care program improvement, systems change and lasting reforms. The overall goal of this project is to increase the number of family members of children with special health care needs who are prepared and supported to become advocates for health care policy and service improvements.

Curriculum Content

The *Project Leadership* seven-session (28-hour) training curriculum is designed to be comprehensive and responsive to family needs. Participants learn about the history of the Disability Rights Movement, increase their knowledge of state and local systems serving CYSHCN, and explore how the legislative process works. They tell their family's story in a way that translates their personal experiences into reflections on the overall systems of care. They learn concrete strategies to influence policies and receive support for identifying and participating in leadership activities. Training emphasizes the value of collaborating with service providers and those making policy and operating programs to improve services, and the importance of continually networking with other advocates and mentors.

Chapter Outline: (See Appendix for a list of learning objectives by chapter.)

Chapter 1	<p>Knowing the Past to Change the Future: <i>History and Purpose of Advocacy</i></p> <p>Key Legislation and Policies; The Disability Rights Movement; What Does It Mean to Advocate?; Current Issues</p>
Chapter 2	<p>Rules of the Road: <i>Systems, Laws, and Entitlements</i></p> <p>How Policies Are Made; Important Laws and Public Systems; Making the Connection: From Individual to Public Policy Advocacy</p>
Chapter 3	<p>Becoming a Mover and Shaker: <i>Working with Decision-Makers for Change</i></p> <p>Your Elected Officials; How Bills Become Laws; The California Budget Process; Providing Testimony; Building Relationships with Legislators; Working with the Media</p>
Chapter 4	<p>Playing Well with Others: <i>Enhancing Communication</i></p> <p>Enhancing Personal Communication Skills; Effective Listening; Partnering with Your Child</p>
Chapter 5	<p>Telling Your Story: <i>Developing and Presenting Stories to Others</i></p> <p>The Importance of Storytelling; Developing Your Story; Presenting and Evaluating Your Story</p>
Chapter 6	<p>Ways You Can Serve: <i>Participating on Decision-Making Bodies</i></p> <p>The Value of Participation; Places to Serve; Plan for Success; Rules for Participation</p>
Chapter 7	<p>Solidifying Partnerships: <i>Connecting with Local Change Makers</i></p> <p>Connecting with Local Leaders and Advocates; Your Action Plan: Presentations and Peer Review</p>

Curriculum Implementation

With a grant from the Lucile Packard Foundation for Children’s Health in 2013, FVCA was able to pilot the training program with two cohorts of parents. During this first year, 30 parents from two FVCA Council Member Agencies completed *Project Leadership* training—10 from the Exceptional Family Resource Center cadre in San Diego in October 2013; and 20 from the Support for Families cadre in San Francisco in February 2014.⁵ The Lucile Packard Foundation for Children’s Health continued its support of the project for a second year. During this time, 25 parents graduated from

⁵ FVCA’s eight Council Member Agencies are local, parent-led family resource centers throughout California. All are also part of California’s Early Start Family Resource Center network that offers parent-to-parent support and helps parents, families, and children locate and use needed services. <http://www.frcnca.org/about-us/>

Family Resource Network in Oakland in November 2014 and an additional 24 parents completed the program in February 2015.

In order to facilitate family participation and retain families in the program, *Project Leadership* incorporates both incentives and ongoing support in its staffing, scheduling and ongoing activities.

Staffing

A Statewide Leadership Liaison works with the FVCA Council to coordinate all project activities. The Liaison trains regional Trainers and provides ongoing technical assistance and support. The Liaison links each Trainer and local project participants to statewide opportunities for advocacy and additional training; maintains a database of opportunities for family participation and a separate database to track families who are available to partner; compiles statewide data, reports and articles; and disseminates project information and results.

The Trainer is responsible for coordinating all aspects of the training in his/her region, including: outreach to and recruitment of participants; planning all meeting logistics such as scheduling, interpreting and childcare; conducting the training using the curriculum resources; and evaluating program components and impact using the curriculum's surveys. The Trainer identifies health-related committees and task forces in the local region and helps project participants become involved. The Trainer assists in developing reports and articles about project activities in the region and maintains regular communication with the Statewide Leadership Liaison. Once the training is completed, the Trainer continues to mentor graduates as they pursue leadership opportunities in the area.

Recruitment and Retention of Families/Caregivers

Recruitment efforts during Phase I and Phase II of the project involved outreach to local agencies and organizations serving children with special health care needs, disabilities, or mental health/behavioral health issues, as well as to pediatric specialty clinics at area hospitals. Flyers and cover letters describing the project were distributed by email, mail and social media. Trainer and host site staff also presented the project information in person at various meetings with representatives from local agencies. In order to recruit a diverse group of parents and caregivers, FVCA did outreach to a wide variety of agencies, organizations and hospitals, including Family Resource Centers, support groups, local California Children's Services county offices and Medical Therapy Units as well as specialty care clinics. This strategy resulted in a diverse group of graduates in terms of race, gender, children's diagnoses, family structure and languages, as well as educational, professional and socioeconomic backgrounds.

Families received stipends upon completion of all seven sessions of the training as well as free childcare and food during the training; these incentives proved very successful in both recruitment and retention of participants. Participants were asked to sign a letter clarifying their responsibilities as part of the project and identifying the time and activities that they were committing to; they also received a certificate of completion at the end of the training.

These strategies enabled FVCA to graduate 79 participants over two years, exceeding its goal of 72.

Scheduling

In order to accommodate a range of family schedules and address the needs of working parents, the seven-session training curriculum is offered in two simultaneous series (i.e., one group that meets on a weekday and another group that meets on Saturdays). The simultaneous series also provides needed flexibility to families coping with the special needs of their children. For example, if a participant registers for the weekday series, but is unable to attend a session, the parent can join the Saturday group that week instead. When a participant is unable to attend either session, s/he can make it up with the Trainer individually or attend the same session within the other concurrent series and still be eligible for the stipend. The curriculum is designed to cover the material in each chapter in three hours. However, offering four-hour sessions is optimal, allowing sufficient time for breaks.

Facilitation

The State Leadership Liaison prepares the local Trainer to present the curriculum and serves as an ongoing coach, providing technical assistance as needed throughout the seven-session training series. Participants receive resource materials and “homework” as well as ongoing support, technical assistance and mentorship at both the local and statewide levels. Families are encouraged to use what they have learned in the curriculum outside in the real world and bring back their experiences to the group at the next meeting. For example, one homework assignment asks participants to research and attend a group, committee, or task force. At the class meeting they are encouraged to talk about what works, the challenges and how they might better be able to participate. As a core feature of the training, participants develop an Action Plan to address issues affecting their own families or families of CYSHCN in general. Training sessions are dynamic and interactive, offering parents the opportunity to learn with and from one another.

Mentoring

A key feature of the training methodology is the provision of support services addressing participant needs and ongoing mentorship, ensuring that families remain engaged in advocacy work. Since the trainings are housed at Family Resource Centers, families have access to individualized support from staff.

In addition to training facilitation, the Trainer maintains regular contact with all project participants both past and current, offering a single point of contact and helping participants connect with advocacy opportunities. The Trainer is also available to provide mentorship to participants on an individual level in person, by telephone, or via email throughout the training series, as well as after graduation. Graduates also attend monthly mentor meetings in which they present their successes and challenges as they pursue advocacy opportunities, share practical advice, and hone their skills with their local Trainer. The Trainer keeps graduates informed of new and ongoing opportunities for participation.

As part of the mentorship component, the State Leadership Liaison developed and maintains two databases: a database of opportunities in which families can participate and a database of family leaders (project graduates) which identifies graduates’ areas of expertise and experiences related to CYSHCN and tracks their advocacy activities. This information builds FVCA’s capacity to be

responsive to media requests and requests for family participation on committees and task forces at the local, regional, and state levels.

During the second year of the project, FVCA developed a *Project Leadership* learning/advocacy community—an online forum moderated by the Statewide Leadership Liaison—so that program graduates from all over the state can learn from and support each other. The goal is to create a forum for sharing resources, events, articles, current issues and important legislation information among all *Project Leadership* graduates. This group serves as an additional forum in which Trainers can provide support and peer mentorship can thrive.

Lessons Learned

The parents who participated in the training learned useful skills for assertive communication, so their ideas on how to improve the *Project Leadership* experience have been thoughtful and well-formulated. They have suggested more attention to cultural differences and learning styles of the group. They also requested more information about the history of the health care system and current issues, such as changes to California Children’s Services (CCS), the state’s Title V program. *Project Leadership* will continue to evolve based on participant input and on new developments in health care and legislation.

FVCA also learned some practical lessons that others interested in implementing the curriculum may want to consider:

- Flexible scheduling, childcare and stipends all proved important in recruiting and retaining participants.
- The long-term mentoring and the facilitated peer support among program graduates have been essential for continued motivation and engagement of graduates.
- Offering a variety of means for communication, mentoring and support helped ensure that all graduates’ needs were met.
- The online forum kept graduates informed about opportunities for involvement beyond their local areas, and helped develop a sense of community with a larger network of families advocating on behalf of CYSHCN.
- FVCA also learned that in order to build on family partnership and encourage growth of parent opportunities, FVCA and host site agencies needed to educate more policymaking agencies about the importance of including families, developing guidelines for family involvement, and removing barriers to family participation.

“I really believe this experience is life-changing for the unexpected role I’ve found myself in of a mother of a special needs daughter... I am proud to be a Project Leadership alum and am excited to see what we all do with our empowered voices.”

Results

The vision of FVCA’s *Project Leadership* is that families of CYSHCN and consumers will be able to effect health care program improvement, systems change and lasting reforms. FVCA projected that parents participating in the training would report that, as a result of their training, they would achieve one or both of the following:

- Identify and/or join one or more disability-related organizations, advocacy groups, task forces, committees, or other related organizations;
- Identify and participate in a decision-making process or provide input on issues affecting CYSHCN at a committee, board, workgroup or other collaborative decision-making body.

After the first twelve months of the project, Health Policy Consulting Group (HPCG) conducted an independent evaluation of the project using the *Family Empowerment Scale*, surveys and interviews of participants. The report concluded: “By 2 months after the training, 87% of participants had joined or identified a disability-related organization, advocacy group, task force, or committee. At the 2-month mark, 61% had participated in a decision-making process affecting children with special health care needs, and an additional 18% had identified an opportunity for the future.”

Some examples of committees and boards that graduates have joined include: UCSF Benioff Children's Hospital Oakland Family Advisory Council; California Children's Services (CCS) of Alameda County Family-Centered Care Committee; Fatherhood Initiative Group, San Francisco County; Title V CCS Needs Assessment; CCS Redesign Workgroups, Children's Regional Integrated Service System (CRISS) Council; Alameda County Committee on Children with Special Needs; Help Me Grow of Alameda County and San Francisco County; Center for Youth Wellness Advisory Council; the San Francisco Mental Health Board; the San Diego Head Start Policy Committee; and the Transition Training Committee for San Diego County.

Graduates have met with local, state and federal policymakers and system administrators to advocate for specific legislation and service improvement. Ten *Project Leadership* graduates visited their state legislators and/or staffers on Legislative Day following the FVCA 2014 Health Summit. In 2015, 16 graduates attended the Health Summit and 15 visited their legislators. Graduates are also staying informed on current issues/legislation affecting CYSHCN/disabilities and are communicating with their legislators via email to express support or concern on specific issues.

Some graduates have provided public testimony since graduating from *Project Leadership*. Two parents gave public testimony at the Assembly/Senate Health Committee hearing regarding out-of-pocket costs for consumers. Three graduates testified at California's Department of Health Care Services (DHCS) subcommittee hearing on proposed changes to the state's Title V CCS program. Another parent gave testimony with a group of parents at the San Francisco Juvenile Justice Commission, presenting her concerns around mental health services for, and adherence to, Individual Education Programs for incarcerated youth. A father presented his story to the San Francisco Board of Supervisors about his housing challenges and his family's desire to remain in San Francisco. He emphasized the additional burden of the scarcity of affordable housing on families of CYSHCN, like his, who need access to resources, medical facilities and specialists for their children.

Additionally, the evaluators found participants to be better prepared to continue to advocate for their children and for systems change:

- From surveys before and after training, participants showed significant, positive changes on measures of empowerment for accessing services for children.

- When tested at the end of their seven-session training sessions, participants' confidence in their ability to advocate, their leadership skills, and their experiences with advocacy showed significant improvement.

“Project Leadership training has allowed me to further build my confidence as an advocate. I have progressively taken on the role as an advocate for [my daughter’s] special health care needs but always felt ‘stuck’ when it came to further advancing. This training has given me the tools, information, and necessary leadership skills to further my advocacy voice for my daughter and other families.”

Recommendations

FVCA *Project Leadership* has been a successful advocacy training program that should be replicated across the state and perhaps beyond the state’s borders. FVCA is seeking out more opportunities to implement the curriculum, which is available to Family Resource Centers and other advocacy organizations on the FVCA website.⁶ Over time, it will be important to further document the impact of advocacy training for parents on the systems upon which their children depend, as well as on the individual families of graduates.

Families

It is strongly recommended that families of CYSHCN seek out official advocacy training prior to joining committees, boards, or other advocacy groups. FVCA also urges parents who have already completed *Project Leadership* or other leadership trainings to maintain their network with other parents by attending meetings or being active on online advocacy groups and to stay informed about current issues related to CYSHCN. Families can receive up-to-date information by joining listservs/ mailing lists distributed by agencies such as FVCA, their local Family Resource Center, and the Lucile Packard Foundation for Children’s Health California Advocacy Network for children with Special Health Care Needs.⁷

Importance of Continuing Mentorship and Support

Based on the experience with this program, ongoing mentorship and support is a crucial element in terms of helping families of CYSHCN continue to stay active and engaged.⁸ As previously reported,⁸ most agencies do not have policies and procedures in place that facilitate family involvement; even after completing training, many family members will need help to locate participation opportunities and ensure that their voices are heard.

⁶ The curriculum can be downloaded from the Family Voices of California website: <http://familyvoicesofca.org/node/3>

⁷ Join the Family Voices of California list serv here: <http://familyvoicesofca.org/node/2> and the Lucile Packard Foundation for Children’s Health Advocacy Network here: <http://lpfch-cshcn.org/advocacy/join-the-advocacy-network/>

⁸ *It Takes a Family: An Analysis of Family Participation in Policymaking for Public Programs Serving Children with Special Health Care Needs in California*, Maryann O’Sullivan, Lucile Packard Foundation for Children’s Health Issue Brief, May 2014.

Outreach to Agencies and Policymaking Bodies

Parent centers will need to continue efforts that encourage agencies and policymaking bodies to actively seek the participation of families, include their input, and support their ongoing partnership. For example, at the annual Health Summit and Legislative Day in Sacramento convened by Family Voices of California, families have many opportunities to speak to policymakers about their children with special needs and their child's value in the community. Families help educate legislators about the systems of care and can suggest more efficient and effective ways to provide services. It's another opportunity for families to put their advocacy skills and knowledge to work.

Conclusion

Project Leadership provides families with convenient, locally focused training, ongoing support, mentoring, linkages to involvement opportunities and information to assist them to become effective public policy advocates. Based on the success of its first two years, it is evident that the training and support this project offers helps families of CYSHCN understand legislative and health care systems, learn to frame their stories as they talk to legislators and key stakeholders, and know how to talk with the media. With their new skills, support, tools and confidence, families can build partnerships with professionals and engage in public policy advocacy on behalf of CYSHCN.

"I feel so empowered and inspired to take my advocacy work to the next level. Project Leadership graciously provided me with the tools and strategies to tailor my story to a specific issue and to be an effective communicator using a balance of emotion and objectivity."

Prior to this project, only a small number of families of CYSHCN in the state were being asked to provide information, education, testimony and committee involvement. By increasing the numbers and diversity of families of CYSHCN prepared to be actively and effectively involved in health care policy and administration, the project has the potential for significant long-term impact. Training family leaders can help raise the profile of CYSHCN in California. The project can increase partnership between families and health care professionals to provide improved care coordination. It will prepare more families to partner in decision-making at all levels, and, ultimately, lead to systems and health care services that are family-centered and easier to access.

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6. The curriculum can be downloaded from the Family Voices of California website: <http://family-voicesofca.org/node/3>
7. Join the Family Voices of California list serv here: <http://familyvoicesofca.org/node/2> and the Lucile Packard Foundation for Children's Health Advocacy Network here: <http://lpfch-cshcn.org/advocacy/join-the-advocacy-network/>
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